

Palliative and Supportive Care (2014), **12**, 495–513.
© Cambridge University Press, 2014 1478-9515/14
doi:10.1017/S1478951513001338

Early integration of palliative care in hospitals: A systematic review on methods, barriers, and outcome

KAREN MARIE DALGAARD, RN, MSC, PHD,¹ HEIDI BERGENHOLTZ, RN, MSC,²
MARIANNE ESPENHAIN NIELSEN, LIBR. DB,¹ AND HELLE TIMM, MSC, PHD¹

¹The Danish Knowledge Centre for Palliative Care, University of Southern Denmark, Copenhagen, Denmark

²The Regional Research Unit, Region Zealand, Roskilde, Koege and Holbaek Hospitals, Denmark

(RECEIVED August 23, 2013; ACCEPTED September 19, 2013)

ABSTRACT

Objective: According to the World Health Organization (WHO), palliative care (PC) should be available to everyone suffering from life-threatening diseases and should be started early on in the illness trajectory. However, PC is often initiated much later and is restricted to cancer patients. There is a need for more knowledge about how early PC can be implemented in clinical practice. The purpose of our study was to document the best evidence on methods for early identification (EI) of palliative trajectories in cancer, chronic heart failure (CHF), and chronic obstructive pulmonary disease (COPD) populations, and to identify preconditions for early integration of general PC in hospitals and outcomes for patients and relatives.

Method: A comprehensive systematic review of methods, preconditions, and outcomes was conducted via an electronic literature search of publications between 2002 and September 2012. A final sample of 44 papers was reviewed in detail.

Results: Our study identified disease-specific and general methods for EI of patients who might benefit from PC. Prognostication of end-stage disease based on (holistic) clinical judgment, prognostic factors, and/or care needs are the most frequently recommended methods. A number of interacting disease-, staff-, user-, and organization-specific barriers need to be overcome in order to implement early integration of PC in clinical practice. Early integration of PC may lead to better symptom management, prolonged survival, and better quality of life.

Significance of Results: No methods can be recommended for routine clinical practice without further validation. There is an urgent need to develop and evaluate methods based on the holistic assessment of symptoms or needs. The barriers to early integration of PC are most extensive with regard to CHF and COPD. Professional training and education are recommended to facilitate early implementation of PC. The evidence about outcome is sparse and mostly relates to cancer populations receiving specialized PC.

KEYWORDS: Early palliative care, Cancer, COPD, CHF, Hospitals

INTRODUCTION

A number of studies indicate that people with life-threatening diseases may benefit from early palliative care (PC) (Mazanec et al., 2009; Temel et al., 2010; Dalgaard, 2010; Murray et al., 2005). When

patients are not identified in timely fashion, the consequences may include inadequate alleviation of symptoms, unexpected emergency admissions, and unplanned institutional death. Patients and their families are denied the opportunity to consider their future on an informed basis, to plan their final time, and to prepare for death (Fischer et al., 2006; Murtagh et al., 2004; Thoosen et al., 2011).

In 2002, The World Health Organization (WHO) emphasized that PC should be available to everyone

Address correspondence and reprints requests to: Karen Marie Dalgaard, Researcher, The Danish Knowledge Centre of Palliative Care, University of Southern Denmark, Strandboulevarden 47B, 1, 2100 Copenhagen, Denmark. E-mail: dalgaard@sdu.dk

affected by a life-threatening disease, and that measures should be initiated early on in the illness trajectory alongside treatment to prolong life (World Health Organization, 2002; Radbruch & Payne, 2009). Even though the debate on these objectives has been going on for quite some time, they have only been implemented to a limited extent in practice (Seymour, 2012; Thoosen et al., 2011). In the first instance, this means that there are inequalities in access to PC (Seymour, 2012). Traditionally, the target group for PC was cancer patients with advanced disease and a short remaining lifespan (Clark & Seymour, 1999; Murtagh et al., 2004; Mazanec et al., 2009; Seymour, 2012). Patients with chronic progressive diseases still have limited access to PC. In addition, there are indications that PC is often initiated late in the trajectory (Albert, 2008; Dalgaard et al., 2010; Gaertner et al., 2010a; Thomas et al., 2011; Iley, 2012).

Early identification of palliative trajectories presents a number of challenges. For one thing, there is no consensus among professionals on when the palliative trajectory begins. The assessment criteria may, for example, be based on the curability of the disease, prognosis, expected remaining lifespan, palliative needs, or a combination of these factors (Department of Health, 2008; Lynn, 2005; Murray et al., 2005; Thomas et al., 2011).

Another issue is that the unpredictable trajectory of the disease may be a challenge. Although various diseases follow a typical course, individual illness trajectories come with a certain amount of unpredictability. Malignant diseases usually have a more predictable progression than nonmalignant ones (Fischer et al., 2006; Murtagh et al., 2004). It can therefore be difficult to decide when PC is appropriate for patients with nonmalignant diseases. This unpredictability can also affect how patients and relatives experience the trajectory. They may have experienced periods of severe disease followed by dramatic improvements (Murtagh et al., 2004). It can thus be difficult to know whether a deterioration of the disease is temporary. This unpredictability can also affect the efforts of healthcare professionals. The excessively optimistic assessment of a patient's life prospects by doctors and a lack of attention on the part of healthcare professionals to decisive changes in the patient's condition can mean that palliative trajectories are not identified in time (Murtagh et al., 2004; Dalgaard et al., 2010).

A third issue is that open communication about palliative treatment aims can be a challenge. Healthcare professionals may be reticent about inviting patients and their families to an explicit open discussion on the subject, partly because they find it difficult and partly because they are afraid of taking

away their hope (Dalgaard et al., 2010). Respect for patients' and families' coping strategies can also mean that an open discussion about PC may be inappropriate, particularly during the early phase of a palliative trajectory (Murray et al., 2005).

The question is how in practice to overcome the challenges that come with early identification of the need for PC. A number of experts maintain that we should nevertheless try, since early identification of the need for PC is a precondition for timely and adequate PC (Murtagh et al., 2004; Lynn, 2005; Murray et al., 2005; Thomas, 2010; 2011; Thoosen et al., 2011). There is a need for more knowledge as to how palliative trajectories can be identified and the challenges overcome.

The aim of our study was to draw up a systematic literature review on the best evidence of methods for early identification (EI) of palliative trajectories for life-threateningly ill patients with malignant and nonmalignant diseases, and to identify preconditions for early integration of general PC in hospitals and the outcomes for patients and relatives. Based on knowledge of the varied progression of diseases and assumptions of inequality in access to palliative measures, the study population included patients with cancer, congestive heart failure (CHF), and chronic obstructive pulmonary disease (COPD).

METHODS

This systematic review was synthesized from the best evidence available. In September 2012, a comprehensive literature search was undertaken of the Cochrane Library, PubMed, EMBASE, CINAHL, PsychINFO, and SveMed+ databases, as well as relevant international websites covering the period 2002 to 2012. Inclusion criteria were: peer-reviewed articles and evidence-based clinical guidelines, written in English, Danish, Norwegian, and Swedish; reporting studies of adult patients with cancer, CHF, and COPD in Western locations (United States, Canada, Australia, New Zealand, and European Union [EU] countries), with a focus on general PC in hospitals.

Devising a search strategy was very challenging due to the lack of MeSH (medical subject heading) terms for this topic area. Our librarian developed the search strategy together with the research team. Table 1 summarizes the search terms employed. Given the diffuse search terms involved, this generated 2,369 titles. The titles and abstracts were screened to exclude articles that were clearly not pertinent. After removal of duplications, 97 papers were read in full, 34 of which met the inclusion criteria. Further hand searches were undertaken by screening the reference lists and citations

Table 1. Summary of search strategy

Diseases

- Pulmonary Disease, Chronic Obstructive OR Neoplasms OR Heart Failure

AND End of Life

- Terminal Care OR Palliative Care OR Terminally Ill OR Critical illness

AND Place

- Hospitals OR Hospital Units OR Hospitalization OR Hospital* (FT)

AND Identification

- Patient Transfer OR Needs Assessment OR Health Status Indicators OR Patient Care Planning OR Patient Selection OR Referral and Consultation OR Outcome and Process Assessment OR Disease Progression OR Prognosis OR Delivery of Health Care OR Critical Pathways OR Continuity of Patient Care OR Health Services Accessibility OR Health Services Needs and Demand

The result of the search above was combined with the searches below with the Boolean operator AND in various ways

Time

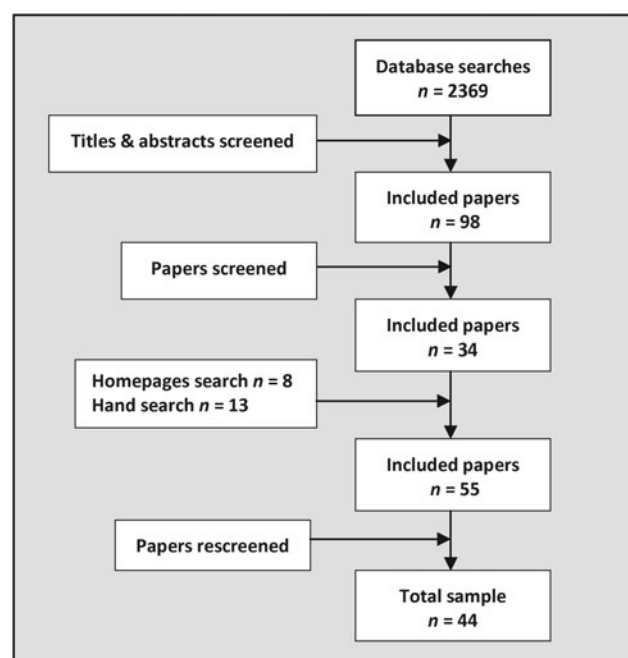
- Timely Identification (FT) OR Early Identification (FT) OR Time Factors

Preconditions

- Family OR Caregivers OR Quality of Life OR Attitude to Death

The search terms varied slightly for each database searched.

of included papers (which yielded 13 papers), and international websites were screened for evidence-based clinical guidelines (yielding 8 guidelines). A total of 55 papers met the study criteria (Fig. 1 outlines this process). Finally, each paper was assessed regarding its methodological standard and validity. Checklists based on objective criteria were employed to increase the transparency and reproducibility of the assessment. For assessment of quantitative studies and systematic reviews, checklists based on the method for evaluating research and guideline evidence (MERGE) were utilized (Sundhedsstyrelsen, 2004). Qualitative methods were assessed using the Critical Appraisal Skills Programme (Critical Appraisal Skills Programme (CASP) (2010)). Clinical

**Fig. 1.** Selection of papers.

guidelines followed the Appraisal and Guidelines for Research & Evaluation (AGREE) instrument (AGREE Collaboration, 2003), which is an internationally recognized instrument for critical assessment of clinical guidelines. Papers of low methodological quality (few or no criteria met), as well as clinical guidelines that could not be recommended according to AGREE (or where there was doubt as to whether or not they could be recommended), were excluded ($n = 11$). A number of “systematic reviews” were classified as “reviews” due to a lack of systematic approach. The final sample included 44 papers.

Our review addressed different objectives, best answered with different methods. Due to the heterogeneity of the sample, the papers included were not rated according to evidence hierarchies (Polit & Beck, 2008). In our study, best evidence was based on findings from methodologically appropriate and valid systematic reviews (6), quantitative (14) and qualitative (6) studies, reviews (9), and evidence-based clinical guidelines (9).

RESULTS

The final sample of 44 reviewed papers is summarized in Tables 2–7 according to primary focus. The results can be categorized as follows: methods specific for cancer, CHF, and COPD; general methods for EI of palliative illness trajectories; preconditions for

Table 2. *Methods for early identification of palliative trajectories in cancer*

Study	Population	Aims	Design	Key Findings
Gaertner et al. (2012), Germany	Hemato-oncological malignancies (862)	To assess at what point in the disease trajectory integration of PC can be achieved To assess interventions delivered by PCST	Chart review, retrospective	Advocate for the provision of disease-specific guidelines to institutionalize early integration of PC
Gaertner et al. (2011b), Germany	19 hemato-oncological malignancies without curative treatment options	To propose and implement an effective approach to early integration of PC	Expert consensus about interdisciplinary disease-specific SOP	SOPs were developed for 19 malignancies: A disease specific point in each disease trajectory to initiate early integration of PC ("green flags") Differentiation of PC assignments ("red flags")
Gaertner et al. (2011a), Germany	Breast cancer patients (83)	To evaluate the effect of institutional recommendations of early integration of PC To assess the point in the disease trajectory for integration of PC	Chart review, retrospective	Administrative directives and PC structure) did not suffice to implement early integration of PC
Gaertner et al. (2010b), Germany	Lung cancer patients without curative treatment options	To develop disease-specific SOP, provide concise definitions of PC structures and competencies to overcome barriers of early integration	Expert consensus about SOP for lung cancer, reflections on pilot study	Disease-specific guidelines for early integration of PC into lung cancer therapy by defining triggers, PC parallel to anti-cancer therapy, specify PC assignments and infrastructure
Gaertner et al. (2010a), Germany	Lung cancer patients (131)	To assess when patients were provided PC and whether earlier integration could be achieved	Chart review, retrospective	The institutional adaptation of "The early integration approach" did not suffice to implement early integration of PC
Glare & Sinclair (2008), Australia	Main focus: advanced cancer	To understand the impact an formulation of prognosis in patients with advanced cancer	Palliative care, review	Cultivate subjective judgment skills in formulating and communicating survival prediction combined with tools
Gripp et al. (2007), Germany	Cancer patients referred to palliative radiotherapy (216) Two physicians The institutional tumor board	To study how survival relates to subjective prediction, objective prognostic factors and individual psychological coping	Cohort, retrospective	Physicians' survival estimates unreliable; self-reported emotional distress and objective prognostic factors may improve the accuracy
Maltoni et al. (2005), Europe (EAPC)	Advanced cancer patients, median survival >90 days	To provide evidence-based clinical recommendations on the use of prognostic factors to determine length of survival	Systematic review	Prognostication of life expectancy is significant (six recommendations developed) Combine clinical experience and evidence from the literature
NCCN (2011), USA	Cancer patients in their last 12 months of life	To develop PC guidelines to facilitate appropriate integration of PC into oncology practice	Clinical guidelines based on evidence and consensus	Procedures for screening based on specific clinical situations Positive screening → integrating PC Negative screening → re-screening at regular intervals
Trajkovic-Vidakovic et al. (2012), Netherlands	Cancer patients in the palliative phase	To determine the prognostic meaning of symptoms in relation to three progressive stages of the palliative phase	Systematic review	Symptoms with independent predictive value are confusion, anorexia, fatigue, cachexia, weight loss, dyspnea, and dysphagia

PC = palliative care; PCST = PC hospital support team; SOP = standard operating procedures; EAPC = European Association of Palliative Care.

Table 3. *Methods for early identification of palliative trajectories in CHF*

Study	Population	Aims	Design	Key Findings
Albert (2008), USA	Advanced CHF	To describe current issues that limit referral to PC	Invited review	Prognostication a problem in CHF CHF guidelines have limited focus on EoLC Research needed to overcome gaps in knowledge
Allen et al. (2008), USA	122 CHF ambulatory patients	To quantify expectations for survival in CHF To compare patient expectations to model predictions To identify patient-related factors associated with discrepancies	Prospective face-to-face survey with quantitative and qualitative questions	Patients overestimate life expectancy relative to model predicted, which may affect decision making regarding EoLC planning
Ezekowitz et al. (2011), Canada	105 patients diagnosed with CHF in an outpatient clinic	To identify CHF patients requiring PC To assess the utility of PC questionnaires ESAS or PPS with KCCQ or NYHA functional class	Cohort, prospective	Modest correlation with NYHA functional class and KCCQ assessment with the PPS and ESAS
Jaarsma et al. (2009), Europe (ESC)	CHF	To address the issue of PC in CHF to increase awareness of the need for PC	A workshop statement, synthesis of presentations and discussions	CHF disease trajectory and triggers for initiating PC goals and discussion
James et al. (2010), USA	214 inpatients with a discharge diagnosis of CHF	To determine if SHFM can identify CHF inpatients who would benefit from timely PC	Cohort, retrospective and prospective Medical records	63% with life expectancy ≤ 1.5 years would have received timely PC had SHFM been used
Levy et al. (2006), USA	Model derived in a cohort of 1125 inpatients with CHF	To develop and validate a multivariate risk model to estimate survival of CHF patients to predict 1-, 2-, and 3-year survival		The SHFM provides an accurate estimate of 1-, 2-, and 3-year survival with use of clinical, pharmacological, device, and laboratory characteristics
Rector et al. (2006), USA	769 patients with primary diagnosis of CHF	To evaluate the predictive validity of a risk score (1-year mortality)	Cohort, retrospective, medical records	The results support the validity of the risk score
Task Force . . . (2008), Europe	Acute and chronic CHF	To update guidelines for the diagnosis, assessment and treatment of acute and chronic heart failure	Guidelines based on evidence and expert consensus	Identify patients suitable for PC, prognosis of end-stage CHF Triggers: clinical features and clinical judgment
Task Force . . . (2012), Europe	Acute and chronic CHF	To update guidelines for the diagnosis, assessment, and treatment of acute and chronic CHF	Guidelines based on review and expert consensus	Difficult to identify a specific timepoint for considering PC Triggers: Clinical, biological, and functional features and clinical judgment
Zambroski (2006), USA	Advanced CHF (NYHA, stage D)	To solve the barrier of lack of prognostic indicators	Clinical review	Recommended methods: adopt NIH criteria for end of life Chronic disease(s) or symptoms or functional impairment and care needs

CHF = congestive heart failure; PC = palliative care; EoLC = end-of-life care; ESAS = the Edmonton Symptom Assessment Scale; PPS = the Palliative Performance Scale; KCCQ = the Kansas City Cardiomyopathy Questionnaire; NYHA = the New York Heart Association Functional Class; SHFM = Seattle Heart Failure Model; ESC = European Society of Cardiology; NIH = National Institutes of Health.

Table 4. *Methods for early identification of palliative trajectories in COPD*

Study	Population	Aims	Design	Key Findings
Iley (2012), UK	End-stage COPD	How to recognize end-stage COPD and incorporate active PC and EoLC discussions	Review	HCP has to overcome difficulties due to identifying end-stage COPD and EoLC discussions Method: incorporate GSF, training and education
Seamark et al. (2007), UK	COPD	Identify patients in the last year of life, time for active treatment and supportive care, and EoLC discussions	Review	Prognostication difficult; recommend methods for identification; clinical judgment by use of the Surprise Question and three disease-specific clinical indicators
Trueman & Trueman (2011), UK	End-stage COPD	Recognition of the palliative phase of COPD	Review	Use tools to help clinicians recognize the palliative phase of COPD combined with training in communications skills
Pinnock et al. (2011), UK	End-stage COPD patients (21) Informal (13) and professional carers (18)	To understand the perspectives of people with COPD as their illness progress, and of informal and professionals caregivers To inform provision of care for COPD patients	Serial qualitative interviews (93) with patients and nominated carers during 18 months	A point of transition to PC is meaningless and impractical in COPD; propose holistic assessment of supportive and palliative care needs triggered at key disease milestones along a lifetime journey with COPD

COPD = chronic obstructive pulmonary disease; UK = United Kingdom; PC = palliative care; EoLC = end-of-life care discussions; HCP = healthcare professional; GSF = Golden Standards Framework.

early integration of general PC in hospitals; and outcomes. The main categories are presented below.

Methods for Early Identification of Palliative Trajectories in Cancer Patients (see Table 2)

Prognostication of Advanced Cancer

Historically, prognostication has been of great importance in identification of palliative trajectories, as the palliative target group was confined to those with incurable illness and a short expected remaining lifespan (World Health Organization, 1990). Prognostication is not explicitly linked to EI of palliative trajectories, but rather with clinical decision making, discussions about therapeutic interventions and quality of life (QoL), and a patient-centered ethical approach to enhance autonomy and help families to make informed choices (Maltoni et al., 2005; Glare & Sinclair, 2008; Trajkovic-Vidakovic et al., 2012).

Prognostication can be based on clinical prediction of survival (CPS), prognostic scores, prognostic indicators, biological parameters, and psychological coping. CPS is a useful and valid tool, but it should be combined with other prognostic factors due to variation in the accuracy of physicians' judgments (Mal-

toni et al., 2005; Gripp et al., 2007; Glare & Sinclair, 2008; Trajkovic-Vidakovic et al., 2012).

Typically, prognostic scores focus on statistical median survival data, with little relevance to the individual patient (Glare & Sinclair, 2008). However, clinicians can use prognostic scores to prepare a general prognosis and CPS to refine an individual prognosis (Maltoni et al., 2005; Glare & Sinclair, 2008). The two most validated and used scales, the Palliative Prognostic Index (PPI) and the Palliative Prognostic Score (PaP), are especially useful in predicting short-term survival (<3 months) and therefore less relevant for EI (Glare & Sinclair, 2008; Trajkovic-Vidakovic et al., 2012). Prognostic scores are available that are useful for predicting survival of greater than three months (Glare & Sinclair, 2008). A full discussion of these issues is beyond the scope of the present paper.

Clinicians can employ patient-related prognostic indicators and a number of clinical signs and symptoms that have proved to be associated with life expectancy. There is strong evidence for performance status, clinical symptoms associated with cancer anorexia-cachexia syndrome, dyspnea, and delirium (Maltoni et al., 2005). However, these indicators are especially relevant for terminal pathways (survival

Table 5. *General methods for early identification of palliative trajectories*

Study	Population	Aims	Design	Key Findings
Boyd & Murray (2010), UK	Patients with advanced long-term conditions, and/or progressive life-limiting illness	To offer guidance about recognizing EoL transitions by the use of clinical judgment	Review	Pragmatic clinical criteria: Identify target group and use of the Surprise question One or more clinical indicator(s) Two or more disease related indicators
Fischer et al. (2006), USA	Patients admitted to general medical wards or medical ICU (sample size 873)	To validate a set of prognostic criteria to identify patients with limited life expectancy (<1 year) who might benefit from PC	Retrospective chart review	The CARING criteria were highly predictive of death at one year in hospitalized veteran population at the time of hospital admission
Hight et al. (2012), UK	People with advanced, incurable conditions; or at risk of sudden, acute deterioration	A tool to identify the target group for assessment and care planning	Clinical guidelines Supportive & palliative care indicator tool	Triggers: general clinical indicators, disease-specific clinical indicators, the Surprise Question
Lunney et al. (2003), USA	4190 descendants >65 year, died from cancer, organ failure (CHF, COPD), frailty and sudden death	To determine if functional decline differs among four types of illness trajectories: sudden death, cancer, organ failure, and frailty.	Cohort, prospective (follow-up six years) Baseline in person interview Follow up 6–10/year Interview within last year of life	Four empirical trajectories of functional decline
Main et al. (2006), UK	All patients with advanced life-limiting illness admitted to hospital	To develop and implement an integrated care pathway	Clinical guidelines The Supportive Care Pathway	A holistic document for all aspects of care, including entry criteria to the pathway (survival >12 months)
Murray et al. (2005), UK	Cancer, organ failure (COPD, CHF), frail elderly	Review currently described illness trajectories at the end of life and draw clinical implications	Clinical review	Three typical trajectories, with varying needs Awareness may help clinicians to meet the multidimensional needs of patients
Thomas (2010), UK	Cancer, organ failure, frailty/dementia	A tool to assist generalist clinicians with timely identification of palliative patients	The GSF clinical guidelines The PIG	To identify patients within the final 12 months. of life Triggers: the Surprise Question, general indicators, Disease-specific indicators Individual needs based coding
Thomas (2011), UK	Cancer, organ failure, frailty/dementia	A tool to assist generalist clinicians with timely identification of palliative patients	GSF Clinical guidelines The PIG	To identify patients within the final 12 months of life Triggers: the Surprise Question, general indicators, Disease-specific indicators Individual needs based coding
Weissman & Meier (2011), USA	Patients with a potentially life-limiting or life-threatening condition, disease or disorder	To select criteria to identify patients at high risk for unmet PC needs To improve general PC	CAPC clinical guidelines Consensus report from CAPC	PC screening assessment tool: Primary and secondary criteria at admission to hospital Primary and secondary criteria for daily rounds

UK = United Kingdom; EoL = end of life; PC = palliative care; CHF = chronic heart failure; COPD = chronic obstructive pulmonary disease; PIG = prognostic indicator guidance; GSF = golden standards framework; CAPC = Center to Advance Palliative Care; PC = palliative care.

Table 6. *Preconditions for early integration of palliative trajectories in cancer, CHF, and COPD*

Study	Population	Aims	Design	Key Findings
Barclay et al. (2011), UK	CHF patients and their HCP	To review the literature concerning EoLC conversations: Prevalence, preferences for their timing and content, facilitators, and blockers	Systematic review	EoLC is rarely discussed; focus is largely on disease management; patient preferences vary; HCPs are unsure, fearing alarm and destroying hope; wait for cues from patient
Boyd et al. (2009), UK	Advanced CHF patients (36), carers (30), & HCP (62) Patients, carers, key professionals (32)	To evaluate the key components of services for people with CHF and recommend how it may be delivered in line with UK policies on long-term conditions EoLC	Serial interviews (162) Focus groups interviews (4)	Prognostic uncertainty hindered consistent proactive PC; patients needing PC should be identified and managed using pragmatic criteria that include proactive shift in care goals
Dalgaard et al. (2010), Denmark	Incurable ill hematological cancer patients, relatives, nursing staff and physicians	To describe the significance of identification and explicit communication of clinical phases in incurable illness trajectories	Participant observation and informal interview Focus groups, HCP interviews (4)	Identifying and explicit communication of transitions in incurable illness trajectories are important preconditions for provision of quality PC
Green et al. (2010), UK	CHF patients	To examine the extent of communication surrounding the potential transition to PC	Narrative review	Themes: barriers to effective communication; patient characteristics; achieving effective communication
Knauff et al. (2005), USA	Oxygen-dependent COPD patients (115) Physicians (89)	To identify barriers and facilitators to patient/physician communication about EoLC	Structured interview with patients Mail survey with physician	A minority of patients (32%) discuss EoLC with their physician Identified a number of specific patient and physician endorsed barriers and facilitators relevant to individual patient–physician pairs
Momen et al. (2012), UK	COPD patients and their HCP	To address issues about EoLC discussions: prevalence, preferences for timing and content, barriers and facilitators	Systematic review	EoLC are rarely discussed. Patient preferences varies HCPs acknowledge the value of conversations, but find them difficult; many prefer patients to initiate them
Selman et al. (2007), UK	CHF patients, NYHA class III/IV(20) Family carers (11) PC and cardiology clinicians (12)	To formulate recommendations for improving EoLC To generate data on patient and carer preferences To investigate communication on EoLC issues	Semistructured qualitative interviews for each sample	Recommendations: sensitive discussions of EoLC issues; mutual education of staff; referral criteria and care pathways
Spathis & Booth (2008), UK	Advanced COPD	To provide an evidence-based approach to overcome barriers to good EoLC	Systematic review	Improving the quality of EoLC lies in overcoming barriers: prognostication difficulties and inadequate communication, and improve ACP discussions, education, and PC service

UK = United Kingdom; CHF = chronic heart failure; COPD = chronic obstructive pulmonary disease; HCP = healthcare professionals; EoLC = end-of-life care; PC = palliative care; COPD = chronic obstructive pulmonary disease; NYHA = the New York Heart Association functional class; ACP = advanced care planning.

Table 7. *Outcome of early integration of palliative trajectories for patients and relatives*

Study	Population	Aims	Design	Key Findings
Temel et al. (2011), USA	151 ambulatory patients with newly diagnosed NSCLC	To assess the accuracy of patient perceptions of prognosis and goals of cancer therapy To examine the effect of early PC on patient illness perception over 6 months To explore if changes in illness perceptions were associated with EoLC	RCT: compare early PC/ standard oncology care vs. standard oncology care alone	Many (69.4%) newly diagnosed patients have an inaccurate perception of their prognosis; early PC significantly improves patient understanding of prognosis over time
Temel et al. (2010), USA	151 ambulatory patients with newly diagnosed NSCLC	To examine if patients receiving early PC experience better QoL, lower rates of depressive symptoms and less aggressive EoLC	RCT: compare early PC and standard oncology care vs. standard oncology care alone	Early PC led to significant improvements in QoL and mood, less aggressive care at the end of life but longer survival compared with patients receiving standard care alone
Wright et al. (2008), USA	Patients with advanced cancer and informal caregivers (332 dyads)	To examine the association between EoL discussions and medical care, patient psychological distress, QoL, and caregiver bereavement	Cohort, prospective, longitudinal; baseline structured interview patients, interview caregivers postmortem	EoL discussions were associated with less aggressive medical care and earlier hospice referrals; Aggressive care is associated with poorer patient QoL and worse bereavement adjustment

NSCLC = non-small-cell lung cancer; PC = palliative care; EoLC = end-of-life; RCT = randomized controlled trial; QoL = quality of life; EoL = end-of-life care.

<3 months). Performance status, nutritional status, dyspnea, confusion, and abnormal laboratory tests (leukocytosis, lymphocytopenia, and elevated C-reactive protein [CRP] levels) are more important in advanced cancer (Maltoni et al., 2005; Glare & Sinclair, 2008). Prognostication in less advanced cancer is typically based on tumor-related indicators (Maltoni et al., 2005; Gripp et al., 2007; Trajkovic-Vidakovic et al., 2012).

Trajkovic-Vidakovic and colleagues (2012) described the prognostic meaning of symptoms in relation to three progressive stages of the palliative phase: (1) disease-directed (advanced cancer, predicted survival 3–12 months); (2) symptom-oriented (far advanced, predicted survival <3 months), and (3) terminal (death imminent). There appeared to be important differences between those relevant to disease-directed and symptom-oriented palliation. Confusion, dyspnea, and fatigue were less relevant in disease-directed palliation.

The prognostic capacity of subjective indicators such as QoL or other psychological parameters is somewhat contradictory but relevant in earlier stages of the disease (Maltoni et al., 2005). Gripp et al. (2007) studied how CPS, objective prognostic indicators, and psychological coping relate to survival. They found a strong impact of psychological distress, namely, depression and anxiety, on survival. Their conclusion was that self-reported emotional distress may improve prognostic accuracy.

Diagnosis-Specific Clinical Assessment

A German research group examined how early integration (EI) of PC can be implemented in routine cancer care (Gaertner et al., 2010a; 2011a; 2012) and concluded that identifying the expected survival time of a specific patient is problematic, and that the use of symptom burden as the only trigger for integration of PC may lead to excessively late PC referrals. They advocated that clinical assessment be based on diagnosis-specific clinical guidelines (Gaertner et al., 2010b; 2011b) and that palliative care be integrated when the therapeutic options for each disease are no longer curative (i.e., life-threatening, incurable and progressive disease). They have defined diagnosis- and stage-specific points at which PC should be integrated into the clinical pathway of 19 hemato-oncological malignancies.

Clinical Holistic Screening

The National Comprehensive Cancer Network (NCCN) developed guidelines to facilitate the integration of PC for cancer patients during their last year of life (National Comprehensive Cancer Network, 2011). They recommended screening proce-

dures based on specific clinical situations: uncontrolled symptoms; moderate to severe distress related to cancer diagnosis and/or therapy; serious comorbid physical and psychosocial conditions; life expectancy greater than 12 months based on objective prognostic indicators (poor performance status, CNS metastasis, delirium, superior vena cava syndrome, spinal cord compression, cachexia, malignant effusions, liver failure, kidney failure, or other comorbid conditions); patient/family concerns about the course of the disease and decision making; and when the patient/family requests PC. They suggested that palliative care should be integrated into general oncology care when patients meet at least one screening criterion.

Methods for Early Identification of Palliative Trajectories in CHF Patients (see Table 3)

Prognostication of End-Stage CHF

A number of prognostic approaches to EI of palliative trajectories in CHF patients have been described. There is a review linking the identification of end-stage CHF and the timing for PC (Albert, 2008). Palliative care begins when a person is diagnosed with a life-threatening or debilitating condition. It is difficult to know when CHF will become debilitating, but no single marker has been found to be more useful than objective and subjective clinical assessment based on prognostic indicators such as poor outcome indicators, activities of daily living, impaired nutrition, and New York Heart Association (NYHA) functional status IV (Albert, 2008).

Prognostic scores can be employed to predict survival (Levy et al., 2006; Rector et al., 2006; James et al., 2010). The Seattle Heart Failure Model (SHFM) provides an accurate estimate of 1-, 2-, and 3-year survival with the use of clinical and pharmacological devices and laboratory variables (Levy et al., 2006, p. 1426). Use of the SHFM in individual clinical situations is not explicitly linked to early identification of palliative trajectories. A model has been developed and validated among outpatients, but it was validated within a cohort of 214 inpatients to determine whether the SHFM could identify patients with a lifespan of less than 1.5 years who might benefit from PC (James et al., 2010). Nevertheless, this model fell short of providing an accurate measure of life expectancy when used in this fashion.

Validation of a risk score for dying within one year of admission for CHF based on vital clinical signs, laboratory tests, and comorbidity also indicates that prediction of individual deaths is far from perfect (Rector et al., 2006).

One study compared patients' subjective self-assessment of life expectancy with model predictions using the SHFM (Allen et al., 2008). Patients tend to overestimate life expectancy regardless of the objective severity of their heart failure. Guidelines developed by the European Society of Cardiology (ESC) recommend a combination of objective indicators and clinical judgment (Task Force for the Diagnosis..., 2008; 2012; Jaarsma et al., 2009). The ESC describes the characteristic trajectory for progressive CHF in three stages: (1) chronic disease management (NYHA I-III), (2) supportive and palliative care phase (NYHA III-IV), and (3) terminal care phase (Jaarsma et al., 2009). PC is relevant in stages 2 and 3, and should be introduced during stage 2. The ESC has also identified points on the CHF trajectory that could act as triggers for PC discussions. These triggers are based on clinical, biological, and functional factors and clinical judgment: frequent admission to hospital or other serious episodes of decompensating despite optimized treatment; heart transplantation and mechanical circulatory support ruled out; chronically poor QoL with NYHA class IV symptoms; cardiac cachexia/low serum albumin; dependence in most activities of daily living; and clinically judged to be close to the end of life (Task Force for the Diagnosis..., 2012).

Integrated Approach

An integrated approach combines identification of patients with advanced CHF and care needs (Zambroski, 2006). The rationale is that patients with advanced CHF must be provided with PC concurrently with life-prolonging intervention, as sudden death can occur at any time, during any phase. Advanced CHF can be identified by adopting the National Institutes of Health (NIH) criteria to define end of life. First, the person must have (a) chronic disease(s) as well as symptoms or functional impairment that persist(s) or fluctuate(s). Second, there must be symptoms or impairments that result from the underlying irreversible disease that require formal or informal care and that can lead to death. Patients meeting these criteria must receive palliative care.

Symptom Assessment

A study by Ezekowitz and colleagues (2011) links clinician- and patient-assessed symptoms and palliative care needs. The principal objective was to assess the utility of PC questionnaires (the Edmonton Symptom Assessment Scale [ESAS] or the Palliative Performance Scale [PPS]) as a supplement to CHF-validated questionnaires (the Kansas City Cardiomyopathy Questionnaire [KCCQ] or The New York Heart Association [NYHA] Functional Class), as traditional CHF

scores alone have not proved clinically useful. This study could not confirm that the PPS or the ESAS was the ideal questionnaire for identifying patients requiring PC. The PPS and ESAS may serve as useful screening questionnaires for symptoms not captured in traditional CHF questionnaires.

Methods for Early Identification of Palliative Trajectories in COPD Patients (see Table 4)

Prognostication of End-Stage COPD

Predicting the prognosis in COPD is difficult due to the uncertain illness trajectory (Seamark et al., 2007; Trueman & Trueman, 2011; Iley, 2012). Three papers linked timely transition to PC and end-stage COPD, defined as patients with severe COPD entering the final 12 months of life (Seamark et al., 2007; Trueman & Trueman, 2011; Iley, 2012). Despite differences, the papers all recommended a combination of CPS and the use of prognostic indicators. To define end-stage COPD, clinicians are recommended to make a clinical holistic assessment by posing the "Surprise Question": "Would I be surprised if my patient were to die in the next 12 months?" With patients for whom the answer is "no," the time has come to initiate PC.

Different prognostic indicators may support CPS. Two papers recommended the use of disease-specific prognostic indicators associated with rapid decline and worsening health status: severely impaired respiratory function (decline in FEV1, dependence on oxygen therapy, severe dyspnea at rest); frequent exacerbations (frequent hospital admissions, ICU stay); severe comorbidity; increasing age, weight loss; and reduced activities of daily living (Seamark et al., 2007; Trueman & Trueman, 2011). Iley (2012) recommended adoption of GSF Prognostic Indicator Guidance (PIG), which recommends use of both general and disease-specific indicators of decline and increasing needs.

Holistic Needs Assessment

The findings from one qualitative study (Pinnock et al., 2011) challenge current assumptions about the transition to palliative care. The policy of identifying a timepoint for transition to PC is meaningless and impractical in COPD. COPD is a condition with no coherent story and an unanticipated end, and the policy has little resonance for people with COPD or their clinicians. Rather than looking for a transition point to switch to PC, their findings propose linking a holistic assessment of palliative care needs with milestones throughout the patient's journey. Suitable milestones might be: diagnosis,

retirement on medical grounds, starting long-term oxygen, hospital admission for an exacerbation, or a positive answer to the Surprise Question.

General Methods for Early Identification of Palliative Trajectories (see Table 5)

Illness Trajectories of Functional Decline and Related Needs

There have been developments in our knowledge of how functional decline and related needs differ among different types of progressive illness (Lunney et al., 2003; Murray et al., 2005). Cancer trajectories are characterized by steady progression and usually a clear terminal phase; organ failure trajectories (COPD and CHF) are characterized by gradual decline, punctuated by episodes of acute deterioration and some recovery, and sometimes more sudden, seemingly unexpected death (Murray et al., 2005). The rationale is that patients with typical illness trajectories and their carers seem to have common patterns of experiences, symptoms, and needs as the illness progresses.

Integrated Tools

The PIG is an integrated tool based on prediction of survival rate and course of decline and increasing needs (Thomas, 2010; Thomas et al., 2011). It aims to assist clinicians in identifying adults who are likely to die within the next 12 months and who may need additional palliative support. The PIG recommends that clinicians employ three steps in the process: (1) the Surprise Question, (2) general indicators of decline, and (3) disease-specific clinical indicators of decline (Thomas et al., 2011). The answer to the Surprise Question is an intuitive holistic assessment based on clinical experience and a range of clinical, social, and other factors that give the whole picture of deterioration. If clinicians are still in doubt, they may use general indicators of decline and increasing needs, based on functional, clinical, therapeutic, and/or biological indicators (Thomas et al., 2011). To support the assessment, clinicians may employ functional assessment tools (the Barthel Index, the PULSE “screening” assessment, or the Karnofsky Performance Status Score). If still in doubt, clinicians may utilize disease-specific clinical indicators developed for a range of diseases, including cancer and organ failure (COPD and CHF). Clinical indicators for cancer focus on indicators of rapid or predictable decline; clinical indicators for COPD and CHF focus on indicators of erratic decline (Thomas et al., 2011). If the answer is “yes” to one or more of the indicators, the process is completed with a needs-based code indicating the remaining lifespan, the actual clinical situation (described as “stable,” “un-

stable/advanced disease,” “deteriorating,” or “dying”), and an individual needs assessment.

The Supportive and Palliative Care Indicators Tool (SPICT), very similar to the PIG (Highet et al., 2012), is a guide for identifying people at risk of dying within the next 12 months. Like the PIG, it recommends indicators to assess the current and future needs of patients and families. However, the indicators are inverted, starting with general clinical indicators of decline, followed by disease-specific clinical indicators of advanced conditions, and, finally, the Surprise Question.

The Supportive Care Pathway (SCP) is an integrated care pathway based on elements from evidence-based national (United Kingdom) guidelines (Main et al., 2006). One reason why the pathway is called the Supportive Care Pathway is that the generalist staff tend to associate palliative care with terminal care. The entry criteria to the pathway are: patients with a life-limiting illness, admitted to hospital following an acute episode, and not expected to survive the next 12 months. No formal evaluations have yet been conducted to assess outcomes for the SCP.

The Centre to Advance Palliative Care (CAPC) has developed a screening assessment tool to identify patients at high risk for unmet palliative needs in hospitals (Weissman & Meier, 2011). Its starting point is identification of patients with any potentially life-limiting or life-threatening disease, disorder, or condition. The screening assessment tool is divided into two checklists: (1) criteria designed for screening at the time of admission to hospital, and (2) criteria designed for daily rounds. Each checklist is divided into *primary* and *secondary* criteria to facilitate ease of implementation. The primary criteria are limited to the most important indicators, global in nature, and to be used as the minimum expected standard of care. The primary criteria at hospital admission are: the Surprise Question, frequent admissions, admission prompted by physical or psychological symptoms that are difficult to control, complex care requirement, and decline in function. Primary criteria for daily rounds are: the Surprise Question, physical or psychological symptoms that are difficult to control, intensive care unit stay (>7 days), lack of care goals, disagreement or uncertainty between the patient and staff, and/or family concern. The secondary criteria are more specific and comprehensive in scope and include physical, psychosocial, and spiritual indicators.

Prognostic Score

The CARING criteria are a simple set of objective prognostic screening criteria applied at the time of hospital admission to identify patients who have a high likelihood of death within one year and who therefore may

benefit from palliative care (Fischer et al., 2006). The criteria for predicting one-year mortality are: cancer as a primary diagnosis, admissions (≥ 2) to the hospital during the past year for a chronic illness, residence in a nursing home, intensive care unit admission with multiple organ failure, and noncancer hospice guidelines (≥ 2 NHPCO criteria). Fischer and colleagues found that the CARING criteria were highly predictive of death at one year in the hospitalized veteran population at the time of hospital admission.

Preconditions for Early Integration of Palliative Care (see Table 6)

There are methods available to help clinicians identify patients eligible for palliative care. However, various barriers in clinical practice need to be overcome if early integration of PC is to succeed (Boyd & Murray, 2010; Thomas et al., 2011). Our review has identified a number of barriers that have a decisive impact on early integration of PC: disease-, staff-, user-, and organization-specific, often with inherent interacting factors documented in cancer, CHF, and COPD populations.

Cancer

Staff-specific: It is an important precondition for the provision of quality PC that the transition to the palliative phase is identified and explicitly communicated to patient and family (Dalgaard et al., 2010). Others highlight formulation and communication about prognosis as a precondition (Maltoni et al., 2005; Glare & Sinclair, 2008). Communicating prognostic information should be part of a therapeutic alliance with the patient (Maltoni et al., 2005). However, physicians are described as barriers to formulation and communication of prognosis due to poor prognostic skills, avoidance, and a reluctant approach (Glare & Sinclair, 2008). Cultivating physicians' subjective judgment skills in formulating and communicating prognostic information is crucial to overcoming barriers of prognostication.

The implementation of the "early integration approach" is highly dependent on the staff perception (or misconception) about PC, which is often mistaken for "terminal care" (Gaertner et al., 2010a; 2011b). Thus, it is important to ensure that the staff attitude toward, and culture of, palliative care become an integral part of patient care.

Organization-specific: There is an urgent need to facilitate institutionalization of the "early integration approach" (Gaertner et al., 2011b). Gaertner and coworkers (2011b; 2012) developed concise definitions of palliative care assignments and infrastructure for institutionalization of the "early integration approach."

CHF

Disease-specific: The most commonly cited barrier to providing PC is the unpredictable illness trajectory and prognostic uncertainty of advanced CHF (Zambroski, 2006; Boyd et al., 2009; Green et al., 2010; Selman et al., 2007). Another barrier is the public perception of CHF as benign compared to cancer (Albert, 2008; Selman et al., 2007).

User-specific: The public perception of CHF as benign may lead to misconceptions at the individual level (Albert, 2008; Selman et al., 2007). These misconceptions may decrease the threat and burden to patients and families and provide hope for the future, but they may lead to fear and anxiety when symptoms worsen despite treatment.

Staff-specific: Inadequate communication surrounding the transition to PC is a frequently reported barrier (Green et al., 2010; Barclay et al., 2011; Selman et al., 2007). The consequence is that end-of-life-care (EoLC) discussions rarely take place at all. The communication challenges are considerable. The unpredictable illness trajectory of CHF, prognostic uncertainty, high risk of sudden death, and compromised patient understanding of their poor prognosis are described as significant barriers to effective communication. In turn, both healthcare professionals and patients hold diverse attitudes towards EoLC discussions in terms of preferences, timing, and content. Lack of adequate communication skills, an unwillingness to disclose sensitive information, ethical challenges due to prognostic uncertainty, different patient preferences, and poor patient understanding underline the need for training professionals in EoLC communication so that they might interact with patients effectively. To overcome barriers of unpredictability, there is a need to shift to a paradigm of blending active (disease-modifying) treatment and palliative care (Zambroski, 2006).

Organization-specific: Interdisciplinary cooperation is of great importance in CHF (Albert, 2008; Green et al., 2010). Collaborative initiatives such as referral criteria, care pathways, and interdisciplinary education are recommended to facilitate collaboration and enhance the mutual understanding of CHF symptom management and PC between cardiac staff and PC clinicians.

COPD

Disease-specific: The greatest challenge to the provision of PC in COPD is prognostic uncertainty due to the unpredictable illness trajectory and unexpected death due to acute exacerbation (Seamark et al., 2007; Spathis & Booth, 2008; Pinnock et al., 2011; Momen et al., 2012; Iley, 2012).

User-specific: Misconceptions about both COPD and PC abound and are important barriers. It

is a sobering thought that patients and caregivers generally fail to appreciate that COPD is a life-threatening disease (Spathis & Booth, 2008). COPD is described as a “way of life” rather than an “illness” that disrupts life (Pinnock et al., 2011). In our death-denying culture, PC can be misunderstood as a sign of “giving up” or that death is imminent (Spathis & Booth, 2008; Iley, 2012). Thus, discussions about prognosis may be avoided by patients and family.

Staff-specific: Prognostication in COPD is difficult, and prognostic uncertainty may lead to “prognostic paralysis” (Seamark et al., 2007). Healthcare professionals need to overcome these barriers to prognostic uncertainty in order to provide early PC. To overcome the challenges caused by the unpredictable illness trajectory, improved prognostication and communication skills are needed (Spathis & Booth, 2008). Inadequate communication surrounding transitions to PC is a frequently reported barrier (Knauff et al., 2005; Green et al., 2010; Barclay et al., 2011; Momen et al., 2012; Selman et al., 2007). The unpredictable illness trajectory of COPD, prognostic uncertainty, high risk of sudden death, and compromised patient understanding of the poor prognosis are significant barriers to effective and timely communication (Green et al., 2010; Barclay et al., 2011; Selman et al., 2007). Furthermore, these barriers foster uncertainty regarding individual patient attitudes, preferences, and the timing of EoLC discussions. Additionally, healthcare professionals do not identify EoLC discussions as their responsibility, and many find it difficult to discuss sensitive subjects such as poor prognosis and palliative care (Iley, 2012). The consequence is that discussions about EoLC are rare in COPD (Knauff et al., 2005; Momen et al., 2012). Good communication skills are a prerequisite to sensitive EoLC discussions, and adequate training in the breaking of bad news is seen as particularly important (Spathis & Booth, 2008; Momen et al., 2012). Staff perceptions of palliative culture are also highlighted as a barrier. A paradigm shift from a disease-oriented approach to a patient-centered PC approach is central to delivery of quality PC (Spathis & Booth, 2008).

Organization-specific: Limited resources are mentioned as significant barriers to delivery of PC (Spathis & Booth, 2008). In particular, interdisciplinary training and education are called for. Respiratory specialists require training in the skills of PC, and PC specialists need more information about the management of nonmalignant disease.

Outcomes for Patients and Relatives (see Table 7)

This section deals with the outcome of early integration of palliative care as it affects patients and

relatives. Many studies have reported a positive correlation between early integration and high-quality PC (Murray et al., 2005; Boyd & Murray, 2010; Thomas et al., 2011). However, there is sparse evidence supporting such statements, and the evidence includes only cancer populations.

A study among patients with newly diagnosed metastatic non-small-cell lung cancer (NSCLC) demonstrated that early integration of PC led to significant improvements in both quality of life (QoL) and mood, and prolonged survival by approximately two months (Temel et al., 2010). It was hypothesized that improvements in QoL and depressed mood may account for the observed survival benefit. The study concluded that early integration of PC with standard oncology for patients with NSCLC may result in better symptom management, leading to prolonged survival and better QoL.

Another study explored NSCLC patients' understanding of the prognosis and goals of cancer therapy, the effect of early PC on patients' illness perception, and the impact of medical decision making at the end of life (Temel et al., 2011). Many patients with newly diagnosed metastatic NSCLC held inaccurate perceptions of their prognoses. However, early PC was found to significantly improve patients' understanding of prognosis over time, and changes of perception were significantly linked to treatment decisions and less aggressive end-of-life care.

A study examined the association between EoLC discussions with physicians and the medical care patients with advanced cancer receive near death, patients' psychological distress, quality of life near death, and caregiver bereavement (Wright et al., 2008). EoLC discussions were found to be significantly associated with less aggressive medical care near death and earlier hospice referrals, leading to better QoL near death. Better QoL near death was associated with better QoL among surviving caregivers, who experienced less regret and showed improvements in self-reported health, physical functioning, mental health, and overall QoL during the bereavement period. Despite physicians' concern that EoLC discussions may cause psychological harm, the study reported no evidence that these discussions were significantly associated with increased emotional distress or psychiatric disorders. Instead, the worst outcomes were seen in patients who did not report having EoLC discussions.

DISCUSSION

This systematic review has identified a number of disease-specific and general methods for early identification of patients with cancer, CHF, and COPD who may benefit from early palliative care. However, a

number of interacting disease-, staff-, user-, and organization-specific barriers need to be overcome if early integration of PC is to succeed. Early integration of PC may lead to better symptom management, prolonged survival, and better quality of life. However, the outcome of early integration of PC has only been examined in cancer populations and among cancer patients receiving specialized PC. We now summarize and discuss the methods for early identification, preconditions, and outcomes.

Disease-Specific Methods

In cancer populations, disease-specific methods for EI of palliative trajectories include the prognostication of advanced cancer, diagnosis-specific clinical assessment, and clinical holistic screening. Despite variation in the accuracy of physicians' judgment, all papers recommend that CPS be combined with prognostic scores, prognostic indicators, and/or biological parameters—all objective indicators of patient-related physical symptoms. The prognostic capacity of patient-reported subjective indicators as psychological distress is uncertain. Prognostic indicators have different meaning and relevance in terminal, far-advanced, advanced, and less-advanced disease. Palliative trajectories have been identified using prognostic factors relevant for advanced cancer (life expectancy 3–12 months). The controversy about confusion and dyspnea has also been identified.

Gaertner et al. (2011b) recommended diagnosis and stage-specific objective clinical criteria to identify patients with incurable, progressive, and life-limiting disease. Their criteria included tumor-related indicators typical for less-advanced disease, indicating earlier identification of palliative trajectories than recommended above. However, the criteria still remain to be evaluated in larger and diverse cancer populations.

The NCCN guidelines recommend screening based on more extensive and holistic screening criteria, which include individual clinical judgment, objective prognostic indicators, and physical and psychosocial symptom burden or needs.

In CHF populations, disease-specific methods for EI of palliative trajectories include prognostication, an integrated approach, and symptom assessment. Prognostication in CHF focuses on identifying end-stage CHF patients who could benefit from PC. One review recommended subjective and objective clinical assessment based on prognostic factors as the best methods so far. Other studies focused on prognostic tools to predict survival on the basis of objective variables. However, such models fall short of predicting individual end-stage CHF. Patient-predicted

self-assessment of life expectancy is not superior to model-predicted life expectancy. Studies of prognostication in CHF are calling for further validation in prospective studies within larger and more diverse populations to strengthen validity and generalizability. The European Society of Cardiology (ESC) recommended a combination of objective criteria and clinical judgment as triggers for integration of palliative care for CHF patients with progressive disease (NYHA III-IV).

An integrated approach recommends integration of PC based on diagnosis of advanced CHF and care needs. This approach places greater emphasis on how the patient trajectory is displayed rather than exact prognostication and takes into account that sudden death can occur at any time, and during any phase. The use of an integrated approach in daily clinical practice is still to be evaluated.

The effectiveness of symptom assessment as an approach to early integration of PC is uncertain. The PPS and ESAS screening questionnaires may supplement traditional CHF questionnaires, but further validation is needed.

In COPD populations, specific methods for EI include prognostication of end-stage COPD and holistic needs assessment. Three papers linked the transition to PC and identification of end-stage COPD (life expectancy >12 months). Prognostication of end-stage COPD is based on clinical holistic assessment, supported by clinical prognostic indicators. Two papers recommended the use of disease-specific clinical indicators, while another recommended adoption of the PIG, which employs both general and disease-specific clinical indicators. The PIG is more extensive in scope and number of indicators than the methods recommending disease-specific indicators. Due to the known difficulties with prognostication of COPD, more formal evaluation of these methods is recommended.

A single qualitative study was critical to the policy of identifying the timepoint for transition to PC care, as this may lead to prognostic paralysis and excessively late referral. This paper proposed linking the holistic assessment of PC needs with key disease milestones throughout the patient's journey, but the implications for daily clinical practice are still to be investigated.

GENERAL METHODS

Three general methods have been described for identification of palliative trajectories: the trajectory approach, integrated tools, and a prognostic tool. Common to all three methods is an emphasis on prognostication based on an assessment of functional decline and related needs.

The trajectory approach combines patterns of functional decline and related needs related to different types of progressive illness. The trajectory approach gives a conceptual overview, but it may be less helpful with a specific individual patient due to interpatient variation in terms of rate of decline and progression, risk of sudden death, and comorbidity. More research is needed to help understand how insights offered by these trajectories can be translated into daily clinical practice. However, considering these trajectories may increase “professional awareness of dying” and lead to integration of palliative care at an earlier stage than would otherwise be the case. The trajectory approach relates to physical well-being. Trajectories related to the spiritual/existential, social, and psychological domains are not mapped. These domains may affect the illness trajectories and have different courses (Grant et al., 2010):

Specific integrated screening tools are recommended: the PIG, SPICT, and SCP tool developed in the United Kingdom and the CAPC tool developed in the United States. The UK screening tools recommend prediction of survival (life expectancy >12 months) as a criterion for potential entry into a PC pathway. The PIG and SPICT tools are very similar. They recommend three triggers to assess the rate and course of decline and the increasing needs of patients and their families: holistic clinical expertise, and general- and disease-specific clinical indicators. The PIG tool is more extensive in scope than the SPICT tool, especially regarding clinical indicators. The main difference is that the SPICT tool inverts the triggers, an expression of clinical indicators having priority over clinical expertise. The SPICT tool is presented in a one-page format. Combined with fewer clinical indicators, it may be less complicated to use in daily clinical practice. Evaluation of the tool is in progress. The PIG has undergone extensive evaluation; however, its acceptance by patients and families has not yet been evaluated. The SCP is a holistic measure addressing all aspects of care, including pathway entry criteria. The SCP has not yet undergone formal evaluation, so that the effect of labeling a pathway “supportive” rather than “palliative” is uncertain.

The CASP tool is somewhat different from the UK tools. The CASP tool recommends identification of patients at high risk for unmet palliative care needs in hospitals. The target group for screening is patients with any potentially life-limiting or life-threatening disease, disorder, or condition—a broad and yet inclusive construct open to variable interpretation. The formulation of criteria for use at hospital admission and for daily rounds ensures continuous, dynamic screening. The criteria are a targeted assessment of care needs rather than functional

decline assessed by the use of clinical indicators. Both primary and secondary criteria are holistic in scope, including assessment of the physical, psychosocial, and spiritual needs of the patient and family.

One study (Fischer et al., 2006) developed a screening tool called the CARING criteria, a predictor of one-year mortality, applied at the time of hospital admission and based on objective prognostic indicators. The CARING criteria were found to be highly predictive of death at one year in a hospitalized veteran population at the time of hospital admission; however, the veteran population is unique (98% male), and the results cannot be applied to a more diverse hospitalized population without further validation.

BARRIERS TO EARLY INTEGRATION OF PALLIATIVE CARE

For cancer, staff-specific barriers to early integration of PC are particularly highlighted. The poor prognostic skills of physicians and their reluctant attitude toward communication of prognostic information to patient and family, as well as staff misconceptions about PC as “terminal care,” are mentioned as important barriers for the “early integration approach.” The papers reviewed do not assign particular attention to disease- and user-specific factors.

For CHF and COPD, a number of similar disease-, staff-, and user-specific barriers form part of a mutually fortifying dynamic process, making it difficult to overcome the identified barriers. The following barriers are part of this process: unpredictable illness trajectory, risk of sudden death, prognostic uncertainty, the public perception of CHF and COPD as benign, compromised patient understanding of their poor prognosis, and a lack of effective communication about EoLC issues combined with a lack of adequate professional communication skills and unwillingness to disclose sensitive information. Interdisciplinary cooperation is of vital importance in enhancing cooperative work and mutual understanding of CHF/COPD symptom management and palliative care.

OUTCOME FOR PATIENTS AND RELATIVES

Two studies based on randomized controlled trials among patients with non-small-cell lung cancer carried out by Temel and coworkers (2010; 2011) concluded that early integration of PC with standard oncology may result in better symptom management, prolonged survival, better QoL, improved patient perception of prognosis, and less aggressive care at the end of life. However, these studies examined the

effect of specialized PC, not general PC. Wright and colleagues (2008) found that integration of PC combined with EoLC discussions among patients with advanced cancer and their caregivers was significantly associated with less aggressive medical care and better QoL near death, as well as better QoL among surviving caregivers.

STRENGTHS AND LIMITATIONS OF THE STUDY

To the best of our knowledge, the present study is the first systematic review to synthesize the literature concerning early integration of palliative care for patients with both malignant and nonmalignant diseases and their families. We consider it a strength that it was built around the best available knowledge in the area, scientific studies, reviews, and clinical guidelines. It provides an overview of the knowledge and recommendations established on the topic so far, indicating gaps and controversy in evidence-based knowledge, and areas of improvement to support implementation of the “early integration approach” in daily clinical practice.

However, the study does have its limitations. The implicit exclusion criteria may have created a publication bias. The scope of included populations and the aims of the study, combined with an intention to select a potentially workable and homogeneous sample, led to exclusion of non-Western locations and papers written in languages other than English (apart from those written in Scandinavian tongues). The search strategy covers the period from 2002, when WHO formulated the “early integration approach.” Thus, potential relevant papers dated before 2002 are not included. However, more of the papers included are built on knowledge acquired prior to 2002. The study focuses on general hospitals. We cannot exclude the possibility that there is relevant knowledge about early integration of PC in other settings, and in specialized PC relevant to hospitals.

While the search strategy was difficult to create, it appears to have been effective, as it was completed by searching the reference lists and citations of included papers. We attempted to reduce the selection bias through the use of objective, reproducible criteria to select relevant publications and assess their validity.

FUTURE DIRECTIONS

This review has identified some of the key issues important to early integration of general palliative care in hospitals for patients with cancer, CHF, and COPD. A number of disease-specific and general methods for EI of palliative trajectories have been identified. Prognostication of end-stage disease

based on (holistic) clinical judgment, different prognostic factors, and/or care needs are the most frequently recommended methods for both malignant and nonmalignant disease. However, this review highlights the controversy and gaps in knowledge regarding methods for EI of palliative trajectories. There is disagreement as to when a palliative trajectory begins. The prognostic models typically take as the starting point when the patient has less than 12 months of life remaining. Others are critical of the use of definite timescales, as that may lead to referrals to PC being made too late. These models recommend referral criteria based on definitions of a potential palliative patient followed by symptom assessment or (holistic) needs assessment. This approach takes into account that PC for cancer patients may be relevant in less advanced stages and, in terms of CHF and COPD, takes into account the risk of sudden death, acute exacerbations, and illness experiences. So far, there is sparse evidence of methods to support this intention.

There is also disagreement about specific clinical indicators and prioritization of the disease-specific and general indicators of end-stage disease, indicating that no prognostic model presented in our review can be recommended for routine clinical use without further validation. However, the prognostic models are the best-evaluated instruments, compared to instruments based on holistic symptoms or needs assessment. There is an urgent need to develop and evaluate methods based on holistic symptom or needs assessment, as they are more inclusive in scope and criteria and may lead to earlier referral to PC than prognostic models.

The papers reviewed here typically report on referral criteria based on objective clinical indicators or physical functioning. Referral criteria based on subjective patient-reported indicators have not been extensively investigated. Very few methods include psychological, social, and existential factors and the perspective of relatives as referral criteria. These factors may be relevant indicators of early integration of PC.

We have identified a number of barriers to the “early integration approach,” most comprehensively regarding nonmalignant diseases. The early integration approach may cause growing tension between active management and the need to communicate an uncertain or poor prognosis. This is a double message that is difficult for clinicians to communicate and for patients and families to receive. There is an urgent need for training, education, and collaborative initiatives targeted at clinicians in order to overcome barriers and facilitate implementation of the “early integration approach” in daily clinical practice. Our review shows that acceptance of the “early

integration approach” by patients and relatives varies widely. Thus, more research about this area is recommended.

The evidence on the effect of early integration of general palliative care in hospitals is sparse. So far, outcomes have been examined in particular in specific cancer populations and among lung cancer patients receiving specialized PC. Further research should be conducted on outcomes in cancer, COPD, and CHF populations to overcome gaps in knowledge and underpin changes in future clinical practice.

REFERENCES

- AGREE Collaboration, The (2003). *AGREE instrumentet: Kursusmanual* [The AGREE instrument: Course manual]. Available at <http://www.kliniskeretningslinjer.dk/images/file/AGREE-Manual.pdf>.
- Albert, N.M. (2008). Referral for palliative care in advanced heart failure. *Progress in Palliative Care*, 16, 220–228.
- Allen, L.A., Yager, J.E., Jonsson, Funk, M., et al. (2008). Discordance between patient-predicted and model-predicted life expectancy among ambulatory patients with heart failure. *The Journal of the American Medical Association*, 299, 2533–2542.
- Barclay, S., Momen, N., Case-Upton, S., et al. (2011). End-of-life care conversations with heart failure patients: A systematic literature review and narrative synthesis. *British Journal of General Practice*, 61, e49–e62.
- Boyd, K. & Murray, S.A. (2010). Recognising and managing key transitions in end of life care. *BMJ*, 341, c4863.
- Boyd, K.J., Worth, A., Kendall, M., et al. (2009). Making sure services are delivered for people with advanced heart failure: A longitudinal qualitative study of patients, family carers, and health professionals. *Palliative Medicine*, 23, 767–776.
- Clark, D. & Seymour, J. (1999). *Reflections on palliative care*. Buckingham: Open University Press.
- Critical Appraisal Skills Programme (CASP) (2010). Available at <http://www.casp-uk.net/> retrieved 31.08.12.
- Dalgaard, K.M. (2010). *Projekt Lindrende Indsats: Hæmatologisk Afdeling, Aalborg Sygehus: Evalueringsrapport* [Project Palliative Care: Evaluation report]. Aalborg: Department of Haematology, Aalborg University Hospital.
- Dalgaard, K.M., Thorsell, G. & Delmar, C. (2010). Identifying transitions in terminal illness trajectories: A critical factor in hospital-based palliative care. *International Journal of Palliative Nursing*, 16, 87–92.
- Department of Health (2008). *End-of-life care strategy: Promoting high-quality care for all adults at the end of life*. London: Department of Health.
- Ezekowitz, J.A., Thai, V., Hodnefield, T.S., et al. (2011). The correlation of standard heart failure assessment and palliative care questionnaires in a multidisciplinary heart failure clinic. *Journal of Pain and Symptom Management*, 42, 379–387.
- Fischer, S.M., Gozansky, W.S., Sauaia, A., et al. (2006). A practical tool to identify patients who may benefit from a palliative approach: The CARING criteria. *Journal of Pain and Symptom Management*, 31, 285–292.
- Gaertner, J., Wolf, J., Scheicht, D., et al. (2010a). Implementing WHO recommendations for palliative care into routine lung cancer therapy: A feasibility study. *Journal of Palliative Medicine*, 13, 727–732.
- Gaertner, J., Wolf, J., Ostgathe, C., et al. (2010b). Specifying WHO recommendations: Moving toward disease-specific guidelines. *Journal of Palliative Medicine*, 13, 1273–1276.
- Gaertner, J., Wuerstlein, R., Klein, U., et al. (2011a). Integrating palliative medicine into comprehensive breast cancer therapy: A pilot project. *Breast Care*, 6, 215–220.
- Gaertner, J., Wolf, J., Hallek, M., et al. (2011b). Standardizing integration of palliative care into comprehensive cancer therapy: A disease-specific approach. *Supportive Care in Cancer*, 19, 1037–1043.
- Gaertner, J., Wolf, J., Frechen, S., et al. (2012). Recommending early integration of palliative care: Does it work? *Supportive Care in Cancer*, 20, 507–513.
- Glare, P. & Sinclair, C.T. (2008). Palliative medicine review: Prognostication. *Journal of Palliative Medicine*, 11, 84–103.
- Grant, L., Murray, S.A. & Sheikh, A. (2010). Spiritual dimensions of dying in pluralist societies. *BMJ*, 341, c4859.
- Green, E., Gardiner, C., Gott, M., et al. (2010). Communication surrounding transitions to palliative care in heart failure: A review and discussion of the literature. *Progress in Palliative Care*, 18, 281–290.
- Gripp, S., Moeller, S., Bölke, E., et al. (2007). Survival prediction in terminally ill cancer patients by clinical estimates, laboratory tests, and self-rated anxiety and depression. *Journal of Clinical Oncology*, 25, 3313–3320.
- Highet, G., Crawford, D., Murray, S., et al. (2012). *Identifying patients with advanced conditions for supportive and palliative care using a clinical indicators tool: SPICITTM*. Available at <http://www.spict.org.uk/> retrieved 28.09.12.
- Iley, K. (2012). Improving palliative care for patients with COPD. *Nursing Standard*, 26, 40–46.
- Jaarsma, T., Beattie, J.M., Ryder, M., et al. (2009). Palliative care in heart failure: A position statement from the palliative care workshop of the Heart Failure Association of the European Society of Cardiology. *European Journal of Heart Failure*, 11, 433–443.
- James, T., Offer, M., Wilson, M., et al. (2010). Increasing palliative consults for heart failure inpatients using the Seattle Heart Failure Model. *Journal of Hospice & Palliative Nursing*, 12, 273–281.
- Knauff, E., Nielsen, E.L., Engelberg, R.A., et al. (2005). Barriers and facilitators to end-of-life care communication for patients with COPD. *Chest*, 127, 2188–2196.
- Levy, W.C., Mozaffarian, D., Linker, D.T. et al. (2006). The Seattle Heart Failure Model: Prediction of survival in heart failure. *Circulation*, 113, 1424–1433.
- Lunney, J.R., Lynn, J., Foley, D.J., et al. (2003). Patterns of functional decline at the end of life. *The Journal of the American Medical Association*, 289, 2387–2392.
- Lynn, J. (2005). Living long in fragile health: The new demographics shape end of life care. *Hastings Center Report*, 35(6) (Suppl.), S14–S18.
- Main, J., Whittle, C., Treml, J., et al. (2006). The development of an integrated care pathway for all patients with advanced life-limiting illness: The Supportive Care Pathway. *Journal of Nursing Management*, 14, 521–528.
- Maltoni, M., Caraceni, A., Brunelli, C., et al. (2005). Prognostic factors in advanced cancer patients: Evidence-based clinical recommendations. A study by the

- Steering Committee of the European Association for Palliative Care. *Journal of Clinical Oncology*, 23, 6240–6248.
- Mazanec, P., Daly, B.J., Pitorak, E.F., et al. (2009). A new model of palliative care for oncology patients with advanced disease. *Journal of Hospice & Palliative Nursing*, 11, 324–331.
- Momen, N., Hadfield, P., Kuhn, I., et al. (2012). Discussing an uncertain future: End-of-life care conversations in chronic obstructive pulmonary disease: A systematic literature review and narrative synthesis. *Thorax*, 67, 777–780.
- Murray, S.A., Kendall, M., Boyd, K., et al. (2005). Illness trajectories and palliative care. *BMJ*, 330, 1007–1011.
- Murtagh, F.E.M., Preston, M. & Higginson, I. (2004). Patterns of dying: Palliative care for non-malignant disease. *Clinical Medicine*, 4, 39–44.
- National Comprehensive Cancer Network. (2011). *NCCN clinical practice guidelines in oncology* (NCCN Guidelines™): Palliative care, version 2.2011. Available at www.nccn.org retrieved 27.09.12.
- Pinnock, H., Kendall, M., Murray, S.A., et al. (2011). Living and dying with severe chronic obstructive pulmonary disease: Multi-perspective longitudinal qualitative study. *BMJ*, 342, d142.
- Polit, D.F. & Beck, C. T. (2008). *Nursing research: Generating and assessing evidence for nursing practice*. Philadelphia: Wolters Kluwer Health/Lippincott Williams & Wilkins.
- Radbruch, L. & Payne, S. (2009). White paper on standards and norms for hospice and palliative care in Europe, part 1: Recommendations from the European Association for Palliative Care. *European Journal of Palliative Care*, 16, 278–289.
- Rector, T.S., Ringwala, S.N., Ringwala, S.N., et al. (2006). Validation of a risk score for dying within one year of an admission for heart failure. *Journal of Cardiac Heart Failure*, 12, 276–280.
- Seamark, D.A., Seamark, C.J. & Halpin, D.M.G. (2007). Palliative care in chronic obstructive pulmonary disease: A review for clinicians. *Journal of the Royal Society of Medicine*, 100, 225–233.
- Selman, L., Harding, R., Beynon, T., et al. (2007). Improving end-of-life care for patients with chronic heart failure: “Let’s hope it’ll get better, when I know in my heart of hearts it won’t.” *Heart*, 93, 963–967.
- Seymour, J. (2012). Looking back, looking forward: The evolution of palliative and end-of-life care in England. *Mortality*, 17, 1–17.
- Spathis, A. & Booth, S. (2008). End-of-life care in chronic obstructive pulmonary disease: In search of a good death. *International Journal of Chronic Obstructive Pulmonary Disease*, 3, 11–29.
- Sundhedsstyrelsen [Danish Health and Medicines Authority] (2004). *Vejledning i udarbejdelse af referenceprogrammer* [Guidelines for the preparation of reference programmes]. Copenhagen: Danish Health and Medicines Authority.
- Task Force for the Diagnosis and Treatment of Acute and Chronic Heart Failure 2008 of the European Society of Cardiology (2008). ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure 2008. *European Heart Journal*, 29, 2388–2442.
- Task Force for the Diagnosis and Treatment of Acute and Chronic Heart Failure 2012 of the European Society of Cardiology (2012). ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure 2012. *European Heart Journal*, 33, 1787–1847.
- Temel, J.S., Greer, J.A., Muzikansky, A., et al. (2010). Early palliative care for patients with metastatic non-small-cell lung cancer. *The New England Journal of Medicine* 363, 733–742.
- Temel, J., Greer, J.A., Admane, S., et al. (2011). Longitudinal perceptions of prognosis and goals of therapy in patients with metastatic non-small-cell lung cancer: Results of a randomized study of early palliative care. *Journal of Clinical Oncology*, 17, 2319–2326.
- Thomas, K.T. (2010). The GSF Prognostic Indicator Guidance. *End of Life Care*, 4(1), 62–64.
- Thomas, K.T. (2011). *The GSF Prognostic Indicator Guidance*, 4th ed. (September 2011) Vol. 4, No. 1: The Gold Standards Framework. London: Royal College of General Practitioners.
- Thoonsen, B., Groot, M., Engels, Y., et al. (2011). Early identification of and proactive palliative care for patients in general practice: Incentive and methods of a randomized controlled trial. *BMC Family Practice*, 12, 123.
- Trajkovic-Vidakovic, M., de Graeff, A., Voest, E.E., et al. (2012). Symptoms tell it all: A systematic review of the value of symptom assessment to predict survival in advanced cancer patients. *Critical Reviews in Oncology/Hematology*, 84, 130–148.
- Trueman, J. & Trueman, I. (2011). COPD: Criteria to assist in the identification of the palliative phase. *British Journal of Nursing*, 20, 635–639.
- Weissman, D.E. & Meier, D.E. (2011). Identifying patients in need of a palliative care assessment in the hospital setting: A consensus report from the Center to Advance Palliative Care. *Journal of Palliative Medicine*, 14, 17–23.
- World Health Organization (WHO) (1990). *Cancer pain relief and palliative care: Report of a WHO Expert Committee*. Geneva: World Health Organization.
- World Health Organization (WHO) (2002). *WHO definition of palliative care*. Available from <http://www.who.int/cancer/palliative/definition/en/>.
- Wright, A.A., Zhang, B., Ray, A., et al. (2008). Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *The Journal of the American Medical Association*, 300, 1665–1673.
- Zambroski, C.H. (2006). Managing beyond an uncertain illness trajectory: Palliative care in advanced heart failure. *International Journal of Palliative Nursing*, 12, 566–573.